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ABSTRACT

This monograph for health care professionals considers the impact that chronic illness and disability have on youth and their families and provides information on adapting principles of family-centered care to promote resilience in adolescents and their families. The monograph stresses the need for community systems of comprehensive services integrated with education, social services, mental health, and family support programs. The eight principles of family-centered care include: (1) recognizing that the family is the constant in an adolescent's life, while service systems and support personnel fluctuate; (2) facilitating adolescent, family, and professional collaboration at all levels of health care; (3) sharing unbiased and complete information among adolescents, families, and professionals in a supportive manner; (4) recognizing strengths and individuality while respecting different methods of coping and honoring cultural diversity; (5) implementing appropriate policies and programs that are comprehensive in therms of providing emotional and financial support to meet the needs of adolescents and their families; (6) understanding and incorporating the developmental needs of adolescents and their families into health care; (7) encouraging and facilitating peer and family-to-family support and networking; and (8) assuring that the design of health care delivery systems is responsive to adolescent and family needs. Family assessment is explained with a sample family genogram illustrated. Strategies that promote the healthy functioning of adolescents with chronic illness and disability and their families are addressed. Collaboration between adolescents, families, and providers during the process of transition is emphasized. (Contains 24 references, and a list of 17 resources whose programs provide direct services to youth and their families, or to individuals, families, and providers. (CR)

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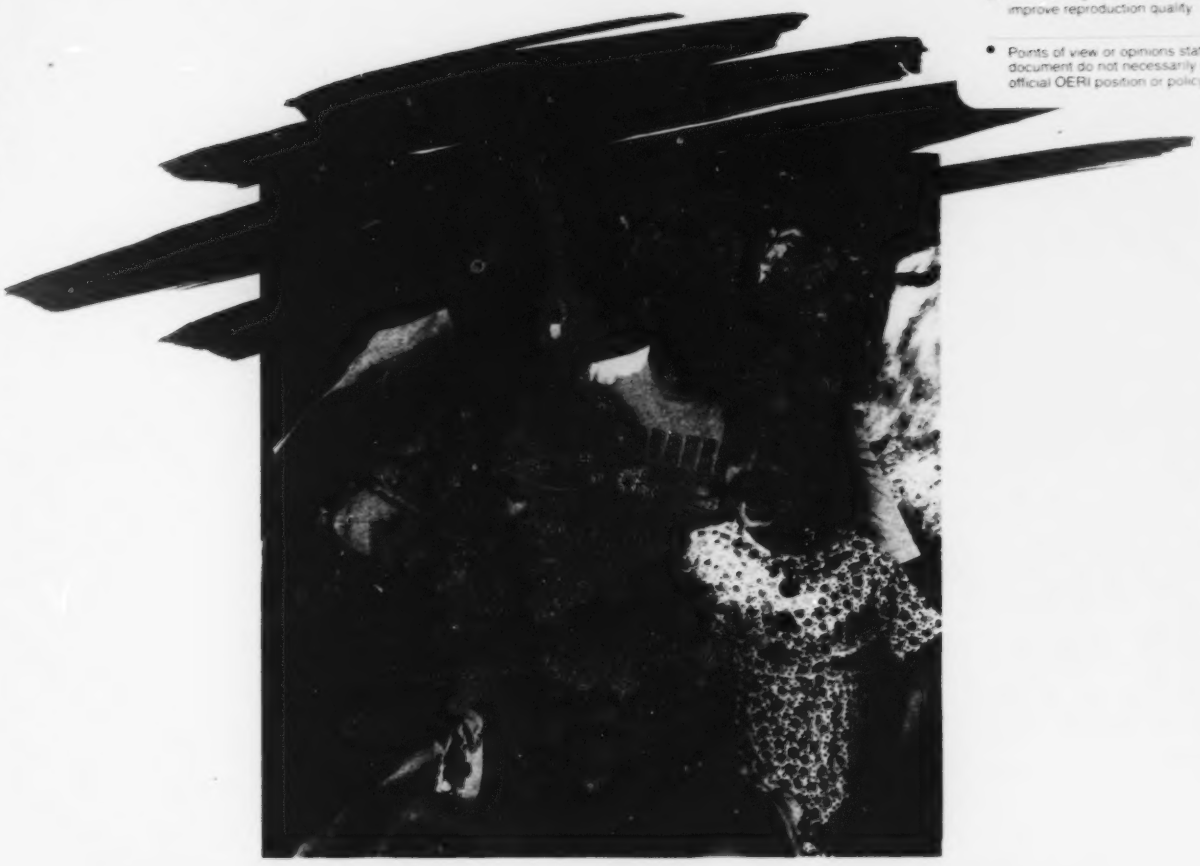

PROMOTING RESILIENCE IN YOUTH WITH CHRONIC CONDITIONS & THEIR FAMILIES

BY ANN E. GARWICK, PH.D. & H.E.C. MILLAR, M.D.

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U.S. Department of Health & Human Services
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TABLE OF CONTENTS

Acknowledgments ..... page 2

Preface ..... page 4

Introduction ..... page 5

The Impact of Chronic Illness & Disability on Adolescents and Families ..... page 7

Principles of Family-Centered Care ..... page 10

Family Assessment ..... page 12

Promoting Healthy Family Functioning ..... page 15

Conclusion ..... page 21

References ..... page 23

Resources ..... page 25

PREFACE

In the past 10 years, recognition of the importance of the family in the child's life has become an accepted principle. The highest priority also is placed on establishing community systems of comprehensive services which are family-centered, culturally competent, and integrated with education, social services, mental health, and family support programs. However, most of the literature and materials on the subject of family-centered care have been written for the benefit of families with small children.

Promoting Resilience builds on an earlier monograph sponsored by The Health Resources and Services Administration's, Maternal and Child Health Bureau, entitled, *Moving On: Transition from Child-Centered to Adult Health Care for Youth with Disabilities. Moving On* was developed to provide guidance and to encourage physicians and other health professionals to tailor their programs and services to the unique needs of youth.

Promoting Resilience recognizes the differing and often unique needs of families and youth as they grow and mature. This book contains strategies for working with families whose children have moved into adolescence, and for whom the issues of development and independence are urgent.

We hope this information will be helpful for a wide variety of providers in the public and private sectors who provide services for adolescents and their families. The information will be useful for physicians; other health disciplines such as psychology, nursing, social work and nutrition; professionals who provide related services such as special education and child development; administrators and program managers; and families.

The challenge to us today is to be nimble enough as an organization, and as individuals, to respond in an age-appropriate way to adolescents and, at the same time, help their families.

Audrey H. Nora, M.D., M.P.H., Director
Maternal and Child Health Bureau
Health Resources and Services Administration
April 1996

INTRODUCTION

Although principles of family-centered care have been clearly articulated and endorsed, less is known about how to implement family-centered care with adolescents and their families. Most of the information about family-centered care has focused on early childhood and school-aged children. Furthermore, the role of families has often been ignored in adolescent literature that focuses on individual development. This monograph addresses these two gaps in the literature by adapting principles of family-centered care to fit the adolescent stage of development and by identifying the impact that chronic illness and disability has on youth and their families.

The negative psychosocial consequences of chronic and disabling conditions have been well-documented in the literature. Fortunately, the majority of youth with chronic conditions and their families function well. However, these adolescents and families are at greater risk for developing mental health problems than their healthy counterparts. The challenge for providers is to identify strategies for preventing and ameliorating these negative consequences. Therefore, this monograph focuses on the theme of promoting resilience—the ability to recover from adversity and adapt to change.

Purpose

- *To promote the principles of family-centered care during adolescence.*
- *To identify strategies that promote the healthy functioning of adolescents with chronic illness and disability and their families.*
- *To enhance effective collaboration between adolescents, families and providers during the process of transition.*

Target Audience

This document is directed primarily towards health care professionals who provide the health and medical care for adolescents with various chronic illnesses and disabilities. The material is applicable to providers who work in primary care settings as well as those who work in multidisciplinary teams. Both generalists and specialists need to know how to provide care that promotes healthy adolescent and family functioning. Yet, health care professionals typically receive little training in how to provide family-centered care to families who have adolescents with chronic conditions.

Scope of Work

This monograph focuses on identifying strategies that health professionals can use to promote resilience and prevent dysfunction in adolescents with chronic and disabling conditions and their families. Until recently, much of the research on youth with chronic conditions and their families has focused on psychopathology and dysfunction. By contrast, resiliency research provides important information on risk and protective factors that providers can use to prevent the negative psychosocial outcomes associated with chronic conditions. In particular, the presence of a supportive family is a critical protective factor that helps adolescents manage the stressors and strains associated with chronic illness and disability. Therefore, clinicians need to be aware of the impact that the chronic condition has on the family so intervention can be designed to support the healthy development and functioning of youth and their families.

This monograph addresses common issues and concerns that adolescents with chronic conditions and their families face, regardless of the particular medical diagnosis. In addition to challenges imposed by the chronic condition, adolescents and their families also experience a number of developmental transitions. While the developmental tasks of adolescents have been well-defined, less attention has been paid to the role that families play during this critical stage of development.

This publication builds on recent work done on transition issues (Moving On, 1992) by identifying the developmental tasks and skills that families need to learn to promote healthy transitions in their adolescents. The goal is to provide information that clinicians can use to address the normal developmental issues and psychosocial concerns of the adolescent within the context of the family.

THE IMPACT OF CHRONIC ILLNESS & DISABILITY ON FAMILIES

The presence of a chronic condition or disability affects the adolescent as well as other family members. The characteristics of the chronic condition (e.g., type of impairment and treatment needed) place particular demands on youth and families (Rolland, 1984). In addition, the adolescent's responses to the condition influence how individual family members and the family as a whole function. Likewise, family members' responses to the chronic condition can impact the young person's physical health and adjustment (Patterson & Garwick, 1994a).

In the future, we hope to see stronger and more specific efforts to support all family members, both as individuals and as a unit. These efforts are needed to counterbalance the demands and negative effects that chronic and disabling conditions can have on families, especially since the day-to-day management of the condition takes place primarily within the context of the family. All too often, the social and psychological aspects of care are overlooked. The psychosocial impact of the condition on the adolescent and family needs to be assessed so resources and intervention can be targeted to the needs of the adolescent and family. Health care professionals can play a major role in decreasing the negative consequences of chronic conditions on adolescents and families by providing care that builds on family strengths and designing intervention that supports healthy functioning.

In practical terms, an adolescent with a chronic condition generally receives a disproportionate share of the family resources—parental time, money, and opportunities for compensatory activities. Other members of the family, particularly siblings, often bear the consequences of inadequate family resources. Therefore, providers need to assess the adequacy of resources for the adolescent as well as other members of the family.

The way in which family functioning is influenced by the presence of an adolescent with a chronic

illness or disability depends upon the overall characteristics and development of the adolescent, the competence of the family, and the demands and limitations posed by the condition. These elements are inextricably entwined. Developmental changes in the adolescent precipitate changes in family functioning. During adolescence, the young person tends to view himself or herself and the condition in a new way. The family's priorities and relationships also change as family members assume new roles and responsibilities and find new ways to balance the demands of the chronic condition with the needs of individual family members.

The Adolescent

Adolescents with chronic conditions have similar health concerns to those of their healthy peers. They are concerned about their physical appearance, peer relationships, sexuality, school performance, substance use and abuse, and work goals. In addition to the management of the condition, clinicians need to address the common concerns of adolescents, especially since studies indicate that adolescents with chronic and disabling conditions report more of these concerns than healthy adolescents (Blum, 1992).

Adolescents often experience new sensations and feelings of doubt about physical attractiveness, sexuality, gender role, and reproductive abilities. These feelings are associated with physiological changes that can be troubling for an adolescent when the chronic condition accelerates or delays pubertal changes (Rosen, 1991; Blum 1992). Sex education is often inadequate, especially when health professionals view youth with disabilities as asexual and ignore sexuality related issues and concerns. Adolescents need accurate information about how their particular condition affects their development and future reproductive capabilities.

The adolescent's social world expands as teens pursue more and more activities outside of the home. Peer relationships are particularly important in adolescent development. However, factors such as environmental barriers, hospitalizations, and stigma can interfere with these relationships. Healthy peers may need information about the specific condition to better understand how to relate to their friend. Information about chronic conditions needs to be available in school settings.

For an adolescent with a chronic condition, the formation of self-identity involves not only the discovery of one's own personality, values, beliefs, and vocational choices, but also the realistic integration of the chronic condition into one's identity and personality. The attitudes and beliefs of peers, family members and providers influence the adolescent's perception of self and their ability to function.

The Family

The family system undergoes marked change during adolescence. Parent/child roles, in particular, shift to allow for the increasing independence of the adolescent. Family relationships between parents and grandparents also change as adolescents establish their own independent relationships with grandparents and other extended family members. Flexible boundaries permit the adolescent to move in and out of the family system, while rigid boundaries hinder their struggle for autonomy (Preto, 1988). Most families are able to change the rules on limits and reorganize themselves to allow adolescents more autonomy while providing appropriate supervision. However, family conflicts are not uncommon during this stage of development as adolescents ask new questions and challenge family rules, beliefs and values. Flexibility and problem-solving skills, rather than power and control approaches, help adolescents negotiate new situations with increasing independence.

Anticipatory guidance about adolescent development needs to be incorporated into office visits for medical concerns. Effective transition planning takes place over time. Adolescents and families need information about limitations, capabilities and strengths that will help them make realistic plans for the future.

The ongoing nature of chronic illness and disability places continual demands on families that can have negative consequences for individuals and relationships among family members. For example, family caregivers are particularly vulnerable to burnout which can be expressed by symptoms such as fatigue, irritability or depression. The couple relationship can deteriorate when parents do not have the time or resources to nurture their

relationship. Siblings and extended family members can also be adversely affected. Providers need to be aware of the ripple effect that chronic conditions have on families and ensure that individual family members and the family as a whole receive adequate support (Patterson and Garwick, 1994a).

Since families provide the majority of care for adolescents with chronic conditions, clinicians must be familiar with, and sensitive to, the impact that chronic conditions have on these families. Families often need information, additional resources and encouragement to prevent chronic conditions from becoming the focal point of their lives. Clinicians play a major role in teaching families how to care for their adolescent's special health care needs along with their normal developmental needs within the context of the family. The goal is to help families balance demands of the chronic condition with the demands of everyday family life.

Limitations imposed by the chronic condition compound the challenges youth and families face in achieving developmental tasks. It can be more difficult for adolescents who are dependent on their parents for physical care to express their own needs. Adolescents who need to rely on others for assistance with daily care need to learn independent as well as interdependent living skills. They also need to know how to advocate for themselves and to manage their condition in home, school and community settings. Families must find ways to promote as much autonomy as possible given the limitations of the particular chronic illness or disability. Arrangements for personal hygiene, sleeping and eating need to be reviewed to ensure that the adolescent receives the greatest possible privacy and independence. Family members and service providers must work together to minimize the hassles and barriers related to managing a chronic condition so the adolescent can invest in other learning opportunities.

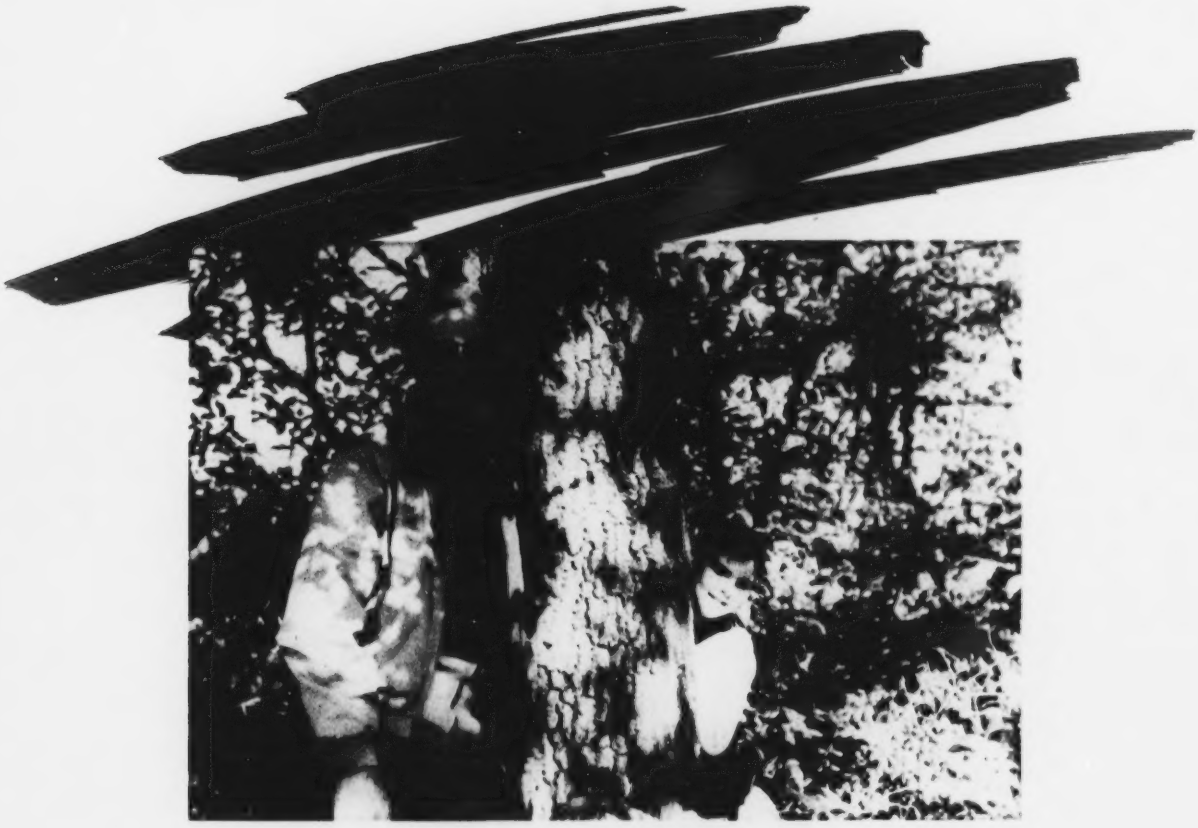
PRINCIPLES OF FAMILY-CENTERED CARE

Most of the work on family-centered care has focused on the needs of young children. A growing body of research on the impact of chronic illness and disability on families of adolescents underscores the need for redefining the elements of family-centered care during adolescence. The principles of family-centered care have been well documented by Shelton and Stepanek (1994) in the monograph, *Family-Centered Care for Children with Specialized Health and Developmental Services*. The wording of these principles has been revised to fit the developmental stage of adolescence.

Clinicians can provide family-centered care during adolescence by:

1. *recognizing that the family is the constant in an adolescent's life while service systems and support personnel within those systems fluctuate;*
2. *facilitating adolescent, family and professional collaboration at all levels of health care;*
3. *sharing unbiased and complete information among adolescents, families and professionals in a supportive manner;*
4. *recognizing the strengths and individuality of adolescents and families while respecting different methods of coping and honoring cultural diversity;*
5. *implementing appropriate policies and programs that are comprehensive in terms of providing emotional and financial support to meet the needs of adolescents and their families;*
6. *understanding and incorporating the developmental needs of adolescents and their families into health care;*
7. *encouraging and facilitating adolescent-to-adolescent and family-to-family support and networking; and*
8. *assuring that the design of health care delivery systems is flexible, accessible, and responsive to adolescent and family needs.*

These principles provide the foundation for our discussion of the role that health care professionals can play in providing care that fosters the adolescent's development and promotes healthy family functioning. Professionals also need to be aware of the importance of cultural beliefs and practices on health behaviors and family attitudes, beliefs and practices. To be effective, treatment plans need to fit within the context of the family and their culture. Providers can avoid the hazards of providing biased care by first listening to the adolescent's and family's definition of the problem. Understanding the impact of the chronic condition on the family helps the clinician provide care that fits the family's values and beliefs.



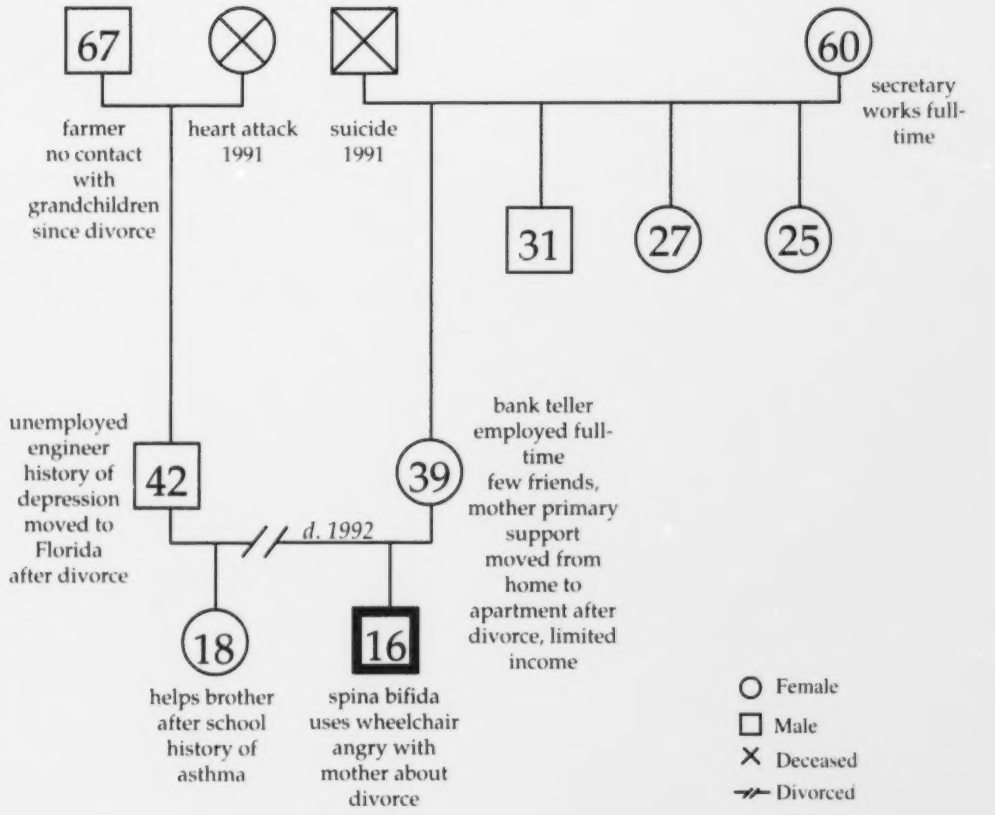
FAMILY ASSESSMENT

Diversity, rather than uniformity, characterizes families of adolescents with chronic conditions (Dawson, 1991; Fine, 1993). Families vary in their structure, types of relationships and household composition. Because of this variability and the importance of understanding chronic illness and disability within the context of the family, we recommend focusing the assessment of family structure on the adolescent's definition of family.

The following questions quickly elicit information about family structure: 1) "Who is in your family?" and 2) "Who lives with you in your home?" From these responses, the practitioner learns which family members are important to the adolescent and who should be included in health care planning. Information about family structure provides important data about the adolescent's support system. It is not unusual for adolescents to include non-blood relatives or pets in their definition of family. This information is missed if the clinician only asks questions about traditional family relationships. Open-ended questions help providers avoid biased assumptions about family composition. In addition, questions about family structure and functioning provide a way for adolescents to discuss family-related issues with providers.

Be aware that living situations for adolescents can shift on a regular or periodic basis. For example, adolescents may alternate households because of joint custody arrangements. The challenge for the provider is to coordinate care with different caregivers and ensure that the adolescent receives adequate health care and needed support in different settings.

A genogram is a helpful tool for recording and tracking information about family structure (McGoldrick & Gerson, 1985; Rogers & Durkin, 1984). Standardized symbols identify structural variables such as gender, age, and generational structure of the family; household composition; and types of relationships between family members. Living arrangements, caregiving roles, significant



Sample Family Genogram

life events, and illness history information can also be recorded on the genogram. Providers can quickly refer to the genogram to gain a sense of the adolescent within the context of the family. In addition, genograms can be used to plan interventions and map progress. The clinician can develop genograms over time as new information is gained in subsequent visits. At least three generations should be recorded on a genogram to gain an understanding of the generational structure of the family and its impact on the adolescent with chronic illness or disability. Extended family members are often involved in caregiving, and youth learn about health and illness from various family members.

In follow-up visits, providers should ask about changes in the family. Changes in the structure of the family (e.g., divorce, separation, remarriage), as well as changes in family functioning (e.g., illness of a parent or increased conflict between siblings), often precipitate changes in how the adolescent's care is managed. New family members may need information about the disability and instruction on how to manage the adolescent's care. Stressful changes in the family may also affect the adolescents' health status.

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In addition to family structure, the provider needs to assess how the family is functioning. Chronic conditions can disrupt parent/child, sibling, and couple relationships in the family. Therefore, it is important to assess the impact of the condition on the family as a whole as well as on subsystems and individuals in the family. Family functioning can be assessed with open-ended questions such as, "How are things going for your family, your brother, husband?" etc. Or, "What problems are hard for you to deal with right now?" The clinician can then follow up with more specific questions to assess particular areas of functioning. An in-depth family assessment is not feasible or needed with each health care encounter. Instead, the goal is to gain an understanding of how the family is doing at each visit. Over time, different subsystems in the family can be assessed. The interest of the provider in the family provides the basis for adolescents and other family members to raise family concerns. Information about family structure and functioning also helps clinicians tailor their intervention to the particular adolescent's and family's needs.

Knowledge about the particular family is requisite to providing family-centered care that is culturally sensitive. In addition, providers need to be aware of their own values and beliefs about families, ethnocultural backgrounds, and chronic conditions. Awareness of one's personal values and beliefs, along with knowledge of the particular family's values and beliefs, helps the professional provide care that fits the family system. Health care professionals can gain knowledge about the adolescent's and family's beliefs and expectations through active listening and respectful inquiry. Findings from our cross-cultural project indicate that families who experienced biased care frequently reported that providers did not listen to their concerns or value their opinions (Garwick, Wolman, Blum, Kohrman, & Wegener, 1994). Open communication and mutual respect between providers and families clearly provide the groundwork for culturally sensitive care. Families need adequate resources and skills to encourage adolescents to take responsibility and manage their own health care.

PROMOTING HEALTHY FAMILY FUNCTIONING

In various studies, inadequate family functioning has been associated with poor physical and psychosocial outcomes in youth with chronic conditions. Poor family functioning decreases the family's ability to comply with home treatment regimens which, in turn, leads to poorer health outcomes. Families who have functioned well in the pre-adolescent years by establishing clear and direct communication patterns are in a better position to work out adolescent challenges than families who have a history of dysfunctional conflict and poor communication skills.

Families at risk include:

1. *parents who have difficulty caring for themselves and other family members in addition to the adolescent with a chronic condition;*
2. *families who focus on one or more members to the exclusion of others;*
3. *families who react to changes with rigid or chaotic responses;*
4. *families with inadequate support networks;*
5. *families who are not able to talk openly with each other about their feelings;*
6. *family members who are overly emotionally involved or disengaged from each other;*
7. *families who dwell on the management of the condition without attending to the developmental needs of the family;*
8. *families who have difficulty managing and adjusting to the chronic illness or disability and making realistic plans for the future.*

Family providers can play a major role in promoting healthy family functioning by building on family strengths and reducing risk factors that contribute to poor outcomes.

A number of investigators have identified individual, family, and community factors that promote resilience in youth and their families

(Hauser, Vieyra, Jacobson, & Wertlieb, 1985; Garmezy, 1991; Resnick & Hutton, 1987; Werner, 1989). Based on an extensive review of the literature, Joän Patterson (1991b) has identified nine aspects of resilient family process that pertain to families of youth with chronic and disabling conditions. These components include:

1. *balancing the illness with other family needs;*
2. *maintaining clear family boundaries;*
3. *developing communication competence;*
4. *attributing positive meanings to the situation;*
5. *maintaining family flexibility;*
6. *maintaining a commitment to the family as a unit;*
7. *engaging in active coping efforts;*
8. *maintaining social integration; and*
9. *developing collaborative relationships with professionals.*

These aspects of resilient family process provide the framework for our discussion of the strategies that health professionals can use to promote healthy family functioning. Providers can enhance family resilience by:

1. *promoting balanced family functioning;*
2. *supporting clear family boundaries;*
3. *developing communication competence;*
4. *fostering positive attributions;*
5. *promoting family flexibility;*
6. *promoting family cohesion;*
7. *supporting active coping efforts;*
8. *encouraging social integration; and*
9. *developing collaborative relationships among adolescents, families and professionals.*

Promoting Balanced Family Functioning

The management of chronic illness or disability takes place within the context of everyday family life. In addition to normative stressors, families of adolescents with chronic illness and disability face added challenges imposed by the chronic condition. Resilient families are able to balance the demands of the condition along with the needs of individual family members.

Developmental transitions often tip the balance in families until new roles and routines are negotiated. A major developmental task for the adolescent is to establish independence from parents and other adults. Limitations imposed by the chronic condition and its management can complicate the adolescent's struggle for autonomy. Teens need to know how to manage their condition along with competing demands and interests. Meanwhile, family caregivers need specific information about the adolescent's particular capabilities and limitations so they can support appropriate levels of independence while providing necessary supervision. In addition to independent living skills, youth with disabilities need to learn *inter*dependent skills—how to co-manage their care with family members and providers. The goal is to promote as much independence for the adolescent as possible given the constraints of the particular condition.

The needs of the adolescent with a chronic condition must be balanced with the needs of other family members. Providers can help families from becoming too tightly organized around the illness or disability by:

1. *identifying and attending to the developmental needs of the adolescent and other family members;*
2. *encouraging adolescents to discover their own hobbies and interests;*
3. *encouraging parents to take time for themselves and their relationships;*
4. *planning treatment regimens with family members so they fit family routines and rituals; and*
5. *providing services that focus on competencies rather than deficits.*

Chronic conditions can easily drain family resources and inadequate resources make it more difficult for families to meet illness and family needs. Youth and families need information about available resources and how to access them. Providers can play a key role in helping families balance illness and family demands by identifying and referring families to appropriate health, education, and community resources. Since the needs of the adolescent and family change over time, the adequacy and relevance of resources must be reevaluated periodically.

Supporting Clear Family Boundaries

Providers in health, education, and social service systems need to be aware of family boundaries and their importance to healthy family functioning. Internal family boundaries differentiate the various sub-systems within the family while external family boundaries set the family apart from the larger community context by defining who is in and out of the family. Families of youth with chronic illness and disability are at greater risk for boundary violations from outside agencies and providers because of their need for services.

Providers can support healthy family functioning by respecting family boundaries. Providers first need to know who is in the family and how the chronic condition affects the family. Clear communication between providers and family members helps maintain clear family boundaries. For example, providers need to be clear with family members about their roles and work together with families to plan care that is minimally disruptive to family routines and rituals. Youth with chronic conditions and their families often work with a number of professionals in a variety of health care, educational and social service settings. Clear communication between providers from different agencies also supports healthy family boundaries. Teens and families need to know which provider to contact for particular issues and problems.

Internal family boundaries typically change as the adolescent moves into young adulthood and independent living situations. Transition planning can help youth and families anticipate changes and clarify family boundaries when the adolescent or young adult leaves home. Clear boundaries make it easier for adolescents and young adults to move on and for parents to let go and establish new internal boundaries.

Developing Communication Competence

One of the developmental tasks for the adolescent with a chronic condition is to develop skills in communicating their own needs and feelings to family members, peers and providers. Communication skills, in turn, enhance the adolescent's sense of autonomy and ability to manage their own health care needs. To support the development of these skills, providers must shift the focus of their inquiry and delivery of information from parents to adolescents.

During the childhood years, parents typically assume the primary responsibility for communicating with health and educational professionals. During adolescence, roles change as the young person has more direct contact with professionals and learns how to manage his or her own condition. Family members and professionals need to learn to work together to help the adolescent gain skills in communicating with health, education and social service providers. For example, youth need to know how to gain access to providers, communicate their needs to providers, and plan care with providers. Youth gain communication skills through active participation in planning their own care (i.e., through involvement in school conferences, family meetings, and health care team meetings). Providers need to ensure that adolescents have a voice in their own health care planning in home, school and health care settings.

Fostering Positive Attributions

Adolescents and their families often search for new meanings about the condition as they experience developmental changes that pose new challenges for them. Adolescents frequently ask questions such as, "Why me?" and "How will this disability affect my future?" Family caregivers typically focus on the impact the condition will have on the adolescent's and family's future.

A growing body of research on chronic illness and disability suggests that the meanings that family members attribute to the condition influence how they adjust to stressful situations (Patterson & Garwick, 1994b). Positive attributions, such as optimistic attitudes about the condition and the child's capabilities, are associated with healthy child and family outcomes. For example, Austin and McDermott (1988) found that parents who had a more positive attitude toward their child's epilepsy were able to cope more effectively with their situation. For the adolescent with a chronic condition, positive attitudes contribute to enhanced self-esteem and a sense of mastery. To the contrary, negative attributions such as a sense of helplessness have been associated with negative outcomes like

depression (Garber, Weiss, & Shanely, 1993; Kazdin, French, Unis, Esveldt-Dawson, & Sherick, 1983). Providers can help youth and families develop positive attributions by providing opportunities for them to talk about what the chronic illness means to them as individuals and as a family. Since peers have a growing influence during adolescence, teens can benefit from talking with other youth who have chronic conditions in one-on-one or group situations. Because meanings are influenced by past experiences and cultural backgrounds, health providers need to assess the family's understandings about the chronic condition. The information helps the provider plan the treatment regimen to fit the family system. Also, misconceptions about the condition or treatment can be corrected and updated information provided.

Providers' attitudes also influence how adolescents and families view their situation. Health professionals can promote positive attributions by reinforcing child and family strengths rather than focusing on deficits.

During adolescence, youth and families are more actively involved in futures planning related to independent living, vocational/educational choices, and moving from pediatric to adult health care settings. Providers can facilitate these transitions by providing opportunities for youth and families to talk with each other about these plans for the future and by referring them to developmentally appropriate resources. Families also need specific, up-to-date information about the chronic condition and the young person's particular capabilities and limitations so they can make realistic plans for the future.

Promoting Family Flexibility

The ability to adapt to changing circumstances is a hallmark of resilient families. A number of studies indicate that positive outcomes in children with disabilities are related to families who are flexible in setting rules, establishing roles, and defining expectations. By contrast, several investigators report that rigidity tends to be associated with overprotectiveness and emotional repression in families of children with chronic conditions (Patterson, 1991b).

During adolescence, teens typically challenge existing family rules as they assume new roles and responsibilities. In reaction to these challenges, parents may react by rigidly enforcing old rules or by abandoning family rules altogether. Teens typically react to these strategies by further testing the rules. However, parents who react to rule challenges by renegotiating the rules to fit the adolescent's new skills while providing a safe structure help the adolescent become more independent. Family flexibility rather than rigidity supports the development of the adolescents' autonomy.

Clinicians can promote family flexibility during adolescence by providing information about normal adolescent development as well as illness management tasks that are developmentally appropriate for the adolescent to achieve. Family conflicts about the management of the condition are not uncommon during adolescence as teens push for more independence and parents adopt new rules and roles. Parents may need assistance in setting developmentally appropriate limits and realistic expectations for their growing adolescent.

Clinicians can model flexibility in their interactions with teens and families. For example, the treatment regimen may need to be redesigned to fit the adolescent's schedule that fluctuates between home, school, work and recreational settings. Realistic expectations on the part of the health care team can help adolescents and their families adjust to changes in the treatment as well as changes in roles that accompany adolescence. Providers can promote flexibility by building choices into the treatment regimen whenever possible. Families may need information on how to adapt the treatment regimen so that they can continue family celebrations and important routines and rituals. Clinicians can also support family flexibility by encouraging family members to take time for themselves as well as each other.

During adolescence, compliance with treatment regimens often decreases as teens assume new responsibilities for their own care. Teens commonly resent barriers to independence imposed by the condition and may resist recommendations from authority figures such as parents and health care

providers. Treatment plans that allow choice and foster the adolescents' autonomy increase the likelihood that the teens will be able to fit the treatment plan into their daily routines. Since experimentation with treatment plans can be expected, youth need to know which aspects of the treatment plan are negotiable and what the consequences are for experimenting with various aspects of the treatment protocol. Adolescents must be actively involved in planning their own care so they can learn how to assume increasing responsibility for their own health care. The goal is to plan care *with* rather than for adolescents.

Promoting Family Cohesion

Family cohesion (the emotional connectedness that links family members together) is a core characteristic of resilient families. A number of resiliency studies have identified family cohesion as a protective factor for adolescents in general (Garmezy, 1991). In addition, family cohesion has been associated with better outcomes in youth with chronic conditions and their families (Patterson & Garwick, 1994a).

Demands of a chronic condition can make it difficult for a family to maintain its connectedness and, particularly, its ability to do things together that they enjoy. The following questions are useful in assessing the adolescent's perspective on family cohesiveness: 1) "What do you do for fun in your family?" and 2) "Who do you feel close to in your family?" The absence of close family members or a lack of family celebrations suggests the need for further assessment and intervention. For example, the clinician needs to determine if the treatment interferes with family celebrations. If so, the family may need information on how to adapt routines and rituals. Families may also need new or additional resources to meet the demands of the chronic condition so that they can enjoy time together. If the adolescent does not have a sense of closeness or connectedness to any adult family members, the clinician should ensure that the teen has a close supportive relationship with another supportive adult since the resiliency literature suggests that a stable, supportive adult relationship is a strong protective factor for adolescents. In sum, interventions need to be designed to support and not undermine family cohesion.

Supporting Active Coping Efforts

Youth with chronic conditions often need to acquire new coping skills as they learn how to manage their condition more independently. Meanwhile, parents and other family caregivers need to assume a less active role in the day-to-day management of the condition and learn new supervisory skills. Roles between providers, youth, and family caregivers also change during the adolescent years as providers work more directly with adolescents and have less interaction with family caregivers.

Providers can facilitate the development of new coping skills in the family by gradually shifting the responsibility of illness care from the parent to child over time as developmentally appropriate. During adolescence, youth need to learn how to become advocates for their own health care.

Providers can help adolescents learn self-care and advocacy skills by providing information about the condition and resources for managing the condition directly to the adolescent. Adolescents must be involved in planning their care with providers. For example, office visits and team meetings need to focus on the needs of the adolescent. Professionals can encourage the active participation of adolescents by listening carefully to their concerns and inviting questions. Active coping efforts contribute to the adolescents' physical health as well as their sense of autonomy and mastery.

Encouraging Social Integration

The presence of chronic illness or disability places the adolescent at risk for social isolation at the very time when peer relationships are a critical factor in adolescent development. The condition and its treatment may limit opportunities for socialization. For example, a wheelchair-bound adolescent may find that transportation barriers and lack of barrier-free environments hinder efforts to get together with friends in the community. Stigma and negative attitudes toward disability also interfere with social integration.

Supportive relationships outside the family are strong protective factors that contribute to family resilience. Numerous studies indicate that families who are proactive in maintaining their social networks are better able to adapt to stressors related to chronic illness and disability. Support networks decrease social isolation and provide a variety of emotional, informational and practical resources for families. Through interactions with others who have adolescents with similar conditions, families learn new skills and discover resources for managing the conditions in a variety of settings.

Clinicians need to assess the adequacy of the adolescent's and family's formal and informal support network. Providers can enhance the adolescent's support network by acknowledging the importance of friendships and encouraging hobbies and extracurricular interests. Barriers that interfere with social relationships need to be identified and adjustments made to accommodate special needs. Teens can benefit from opportunities to talk in individual or group settings with other teens or young adults who have faced similar challenges. Support groups and camp experiences also provide opportunities for teens to develop a variety of coping skills and a sense of confidence while socializing with peers.

Developing Collaborative Relationships

Facilitating family/professional collaboration at all levels of hospital, home and community care is a key element of family-centered care (Shelton & Stepanek, 1994). Effective partnerships require the active participation of professional service providers as well as adolescents and their families. Supportive collaborative relationships help adolescents develop a sense of competence as they assume increasing responsibility for their own care. Similarly, effective family/professional collaborative relationships help parents establish new patterns of behavior and let go of unnecessary roles as adolescents grow into adulthood.

Providers can promote healthy collaborative relationships by:

a) listening to, and respecting, the adolescent's and family's understanding of the condition and its impact on the family;

b) including the adolescent and family caregivers in decision-making about the management of the condition;

c) sharing up-to-date, relevant information about the chronic illness or disability with adolescents and family caregivers;

d) working together to manage rather than control particular situations; and

e) providing developmentally appropriate information and guidance.

Transitions from pediatric to adult health care settings pose new challenges and opportunities for youth and their families. Collaborative relationships between pediatric and adult health care providers not only facilitate the transfer of care but also promote the development of new collaborative relationships between the young adult, the family, and adult health care providers.

CONCLUSION

While the life expectancy for youth with chronic conditions has improved dramatically, less attention has been paid to enhancing the psychosocial development of youth and families. All too often, intervention focuses on the disability alone and adolescent health care issues and normal developmental needs are overlooked. However, health care professionals are in key positions where they can influence both physical and mental health outcomes, particularly because of their ongoing contact with youth with chronic conditions.

Research on resilient youth and families suggests specific strategies providers can use to promote healthy functioning. The fact that youth with chronic and disabling conditions and their family members face about a twofold risk of mental health problems (Gortmaker, Walker, Weitzman, & Sobol, 1990; Lavigne & Faier-Routman, 1992) underscores the importance of integrating strategies that promote positive mental health into existing health care services for these populations. In addition, health care for adolescents with special health care needs must be delivered with conscious attention to the family context since the family plays such an integral role in the adolescent's development and day-to-day care. Clinicians need to provide care that supports healthy family functioning and avoid strategies that undermine family functioning (e.g., planning rigid treatment protocols and making decisions for, rather than with, families).

The following three recommendations for treatment plans promote resilience in youth with chronic conditions and their families.

1. Include the Adolescent and Family in Treatment Plans

Youth and families obviously play a major role in the day-to-day management of the chronic condition. Therefore, providers need to understand the impact that the chronic condition has on everyday life so realistic treatment plans can be

designed. Problems arise when treatment plans do not consider the social context within which the adolescent lives. Treatment plans should minimally disrupt family life and enhance the healthy development of the adolescent.

Providers can include families even when they are not physically present during office visits. For example, information about the family can be gathered from the teen. The goal is to gain an understanding of the adolescent within the family context.

2. Build Treatment Plans Based on the Adolescent's Strengths and Abilities

Identifying strengths and capabilities helps providers design interventions that build competencies in adolescents with chronic conditions. In addition, youth need specific information about their particular strengths and limitations so they can make realistic plans for future career, educational and living arrangements. By contrast, services and programs that are solely based on deficits can limit the adolescent's potential, particularly when funding for services is dependent on demonstration of certain degrees of continued impairment.

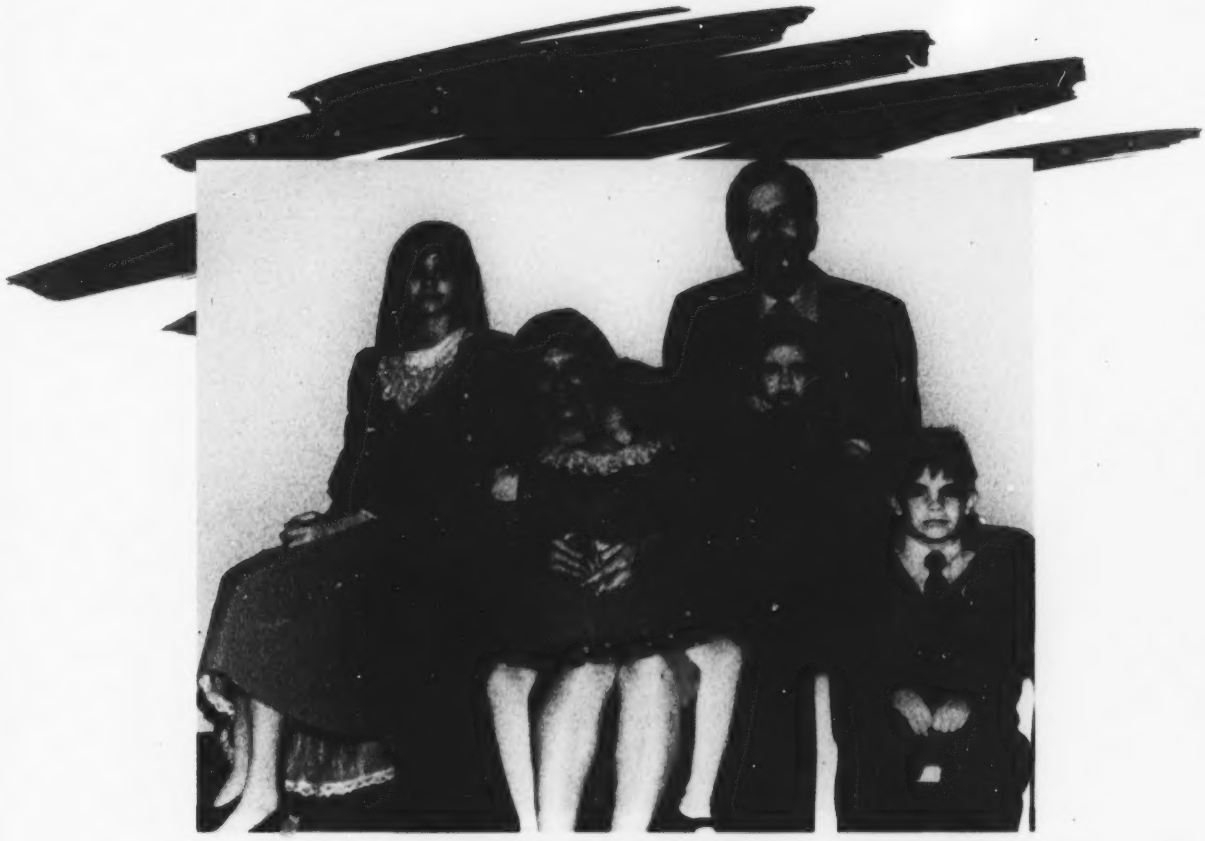
3. Address the Normal Developmental Needs of Youth and Families

The medical condition typically becomes the focus of attention in encounters with service providers and health concerns often are ignored. Since adolescents with chronic conditions are more like their healthy peers than unlike them, health care concerns common to adolescents must be addressed. Youth with chronic conditions deserve comprehensive care that addresses adolescent health and disability-related issues.

Furthermore, parents and other family caregivers need to find new ways for managing the chronic condition as the adolescent moves into adulthood. Providers can ease transitions by incorporating developmentally appropriate information and instruction into office visits over time, beginning at an early age. Treatment plans need to be evaluated periodically to ensure that they fit the developmental stage and capabilities of the young person. Developmental issues must be integrated into treatment plans to foster the healthy functioning of youth and families.

The challenge...

Providers must decrease the risk of negative mental health outcomes associated with chronic illness and disability. By implementing strategies that promote resilience, health care professionals can improve the quality of life for youth and their families.



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RESOURCES

The following programs provide direct services to youth with disabilities and their families.

Adolescent Employment Readiness Center (AERC)
Children's National Medical Center
111 Michigan Ave. N.W.
Washington, DC 20010-2970
(202) 884-3203

Activities include an annual career awareness conference, advocacy training, community outreach, job placement services, and individual career counseling for students with chronic illnesses and physical disabilities.

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Handicapped's Only a Word (HOW)
HOW, Inc.
Cooperative Extension Service
18410 Muncaster Rd.
Derwood, MD 20855
(301) 590-9638

This innovative program for teens with physical disabilities, their parents, and their teenage siblings focuses on social interaction, education, instructional resources, psychological development, and just plain fun! The program includes a teen advisory board, a parent advisory board, and a community advisory board.

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National Jewish Center for Immunology & Respiratory Medicine
1400 Jackson St.
Denver, CO 80206
1-800-LUNG (5864)

National Jewish operates a variety of psychosocial interventions for adolescents with respiratory and immune disorders and their families, including the Adolescent Day Program, outpatient clinics, short-term youth and family programs, and a school program for students with any medical condition. The focus of the Adolescent Day Program is on strengthening the family's coping skills and enabling adolescent emancipation and autonomy.

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Project Launch: The Independent Living Clinic for Adolescents
University of Minnesota, Box 721
420 Delaware St. S.E.
Minneapolis, MN 55455
(612) 623-5041 (Gee Gee Selden) or (612) 626-2825

A program to assist adolescents with chronic conditions and their families in successfully making the transitions to adulthood. Areas included are education, work, social relationships, physical, emotional and sexual health. A team of professionals works with the individual and his or her family to sort through problem areas and identify strategies that will enable the greatest possible independence.

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Project Youth
PACER Center
4826 Chicago Ave. S.
Minneapolis, MN 55417-1055
(612) 827-2966

Project Youth is a program dedicated to family involvement in transition planning. It will assist teens with disabilities in recognizing and working toward potential and future goals. The project will provide training to state agency staff members on family-centered transition planning.

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Youth in Preparation for Independence
c/o Massachusetts Office on Disability
One Ashburton Pl., Room 1305
Boston, MA 02108
(617) 727-7440

Youth with physical, sensory, or learning disabilities come together in a series of educational and networking sessions to explore lifestyle options, learning about resources and coping strategies, and the development of skills which will enhance independence. A concurrent program is offered to parents.

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The following national information resource centers offer assistance to individuals, families and providers.

The Benefits Resource Network
Kennedy Krieger Community Resources
Department for Individual & Family Resources
2911 E. Biddle St.
Baltimore, MD 21213
800-677-9675

A specialized information, training, advocacy and technical assistance service that provides expert information about Social Security benefits (SSI and SSDI) for persons with disabilities and their family members.

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Family Voices
Box 769
Algodones, NM 87001
(505) 867-2368 or (505) 867-6517 (Fax)

A national grassroots organization of families of children with special health care needs. Its purpose is to ensure that families and children are not forgotten as state and national health care reform initiatives take place.

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HEATH Resource Center
National Clearinghouse on Postsecondary Education for Individuals with Disabilities
One Dupont Circle, Suite 800
Washington, DC 20036-1193
800-544-3284

A clearinghouse which collects and disseminates information nationally about disability issues in postsecondary education, including educational support services, policies, and procedures related to educating or training people with disabilities after they have left high school.

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Institute for Family-Centered Care
7900 Wisconsin Ave., Suite 405
Bethesda, MD 20814
(301) 652-0218

By promoting collaborative, empowering relationships between providers and consumers, the Institute facilitates family-centered changes in all settings where children and families receive services and support. The Institute seeks to increase understanding and practice of family-centered care through development of print and audiovisual resources, information dissemination, policy and research initiatives, training, and technical assistance.

National Center for Education in Maternal and Child Health (NCEMCH)
2000-15th St. N., Suite 701
Arlington, VA 22201-2617
(703) 524-7802

NCEMCH develops, collects, and disseminates information and educational materials on maternal and child health; collaborates with public agencies, voluntary and professional organizations, research and training programs, policy centers, and others to improve the health, education, and well-being of children, youth and families.

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National Center for Youth with Disabilities (NCYD)
University of Minnesota, Box 721
420 Delaware St. S.E.
Minneapolis, MN 55455
(612) 626-2825

An information, policy, and resource center focusing on adolescents with chronic illnesses and disabilities. NCYD maintains the National Resource Library, a database of comprehensive information to assist researchers, planners, service providers, parents and youth. Publications include a newsletter, a series of topical annotated bibliographies, and a series of fact sheets.

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National Information Center for Children and Youth with Disabilities (NICHCY)
P.O. Box 1492
Washington, DC 20013
800-695-0285

Provides free information to assist parents, educators, and advocates in helping children and youth with disabilities participate as fully as possible in school, community, and home life. An information specialist can provide personal responses to specific questions, referrals to other organizations, information packets, publications on current issues, and technical assistance to parent and professional groups.

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Research and Training Center on Family Support and Children's Mental Health
Regional Research Institute
Portland State University
P.O. Box 751
Portland, OR 97207-0751
(503) 725-4175
800-628-1696 (Family Resource Clearinghouse)

Activities focus on improving services to families whose children have mental, emotional, or behavioral disorders through a set of related research and training programs. A clearinghouse serves families of children with serious emotional disorders and offers national toll-free telephone service, a databank, a series of fact sheets, and a state-by-state resource file.

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Society for Adolescent Medicine (SAM)
1916 N.W. Copper Oaks Circle
Blue Springs, MO 64015
(816) 224-8010

The Society for Adolescent Medicine, a multidisciplinary organization, is devoted to the development of comprehensive acute, chronic and preventive health care delivery to youth, and to the institution of imaginative scientific research regarding all aspects of adolescence. The Journal of Adolescent Health is SAM's official publication.

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The Sibling Support Project
Children's Hospital and Medical Center
P.O. Box 5371, CL-09
Seattle, WA 98105-0371
(206) 368-4911

This project seeks to enhance services for families of children and youth with chronic conditions through the development of peer support and education programs for brothers and sisters of persons with disabilities. Staff provide training, technical assistance, demonstration, and resource materials to facilitate the development of sibling support programs.

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Parent Training and Information Centers (PTI)
Technical Assistance to Parents Program (TAPP)

The PTI programs are a national network of parent-run projects designed to provide training and information to parents of children and youth with disabilities and persons who work with parents to enable them to participate more effectively with professionals in meeting the educational needs of children and youth with disabilities. There are 71 PTI programs in the United States and Puerto Rico. Four TAPP Regional Centers and TAPP's central office provide technical assistance to parent centers and can refer families to their state's PTI program.

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TAPP Project Central Office

Federation for Children with Special Needs
95 Berkeley St., Suite 104
Boston, MA 02116
(617) 482-2915

TAPP Regional Centers

West: Washington PAVE
6316 S. 12th St.
Tacoma, WA 98465
(206) 565-2266

Midwest: PACER Center
4826 Chicago Ave. S.
Minneapolis, MN 55417
(612) 827-2966

Northeast: Parent Information Center
151A Manchester St.
P.O. Box 1422
Concord, NH 03302
(603) 224-7005

South: Exceptional Children's
Assistance Center
P.O. Box 16
Davidson, NC 28036
(704) 892-1321

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